The Canadian Addison Society
La Société canadienne d’Addison

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PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.

Annual General Meeting:

Remember that the next annual general meeting is coming up. We hope that members on the Lower Mainland and Island (BC) can join us, as well as members from across Canada who may want a vacation in wonderful Vancouver. If you require billeting, please contact Judy Stanley at bugbee@shaw.ca or (604) 936-6694.

It will be held Saturday, October 16, 2010, 1:00 to 4:30, in Vancouver, in the Sherbrooke Building, Sherbrooke Lounge, 260 Sherbrooke Street, New Westminster, BC.

Agenda:
1) Registration
2) President's Report
3 Minutes of the 2009 AGM
4) Election of Board Members
5) Financial Report
6) Membership Update
7) Director's Reports

8) New Business
9) Speaker - Dr. Robert Sharpe, Anesthesiologist & Critical Care Medicine
10) Socializing

We are fortunate to have Dr. Sharpe, a highly qualified Anaesthetist, as guest speaker. He will be the first anaesthetist we've had to speak to the group, so it should be very interesting. Those of you who will not be attending the meeting may e-mail questions for Dr. Sharpe to Marilyn Thauberger at thaubergers@shaw.ca. Answers will be published in the meeting minutes.

If you expect to attend the meeting, please advise the organizers using the form attached to this newsletter. You can email bugbee@shaw.ca or send by Canada Post to Judy Stanley,
5 Tuxedo Place, Port Moody, BC V3H 3W5.

Board Decisions:

- The Board has authorized sending complimentary print copies of the newsletter to all endocrinologists in Canada, on a rotating basis, to help make them aware of the Society and what it can offer. July 2010's newsletter was sent to all endocrinologists in Ontario, and we will send this one (October 2010) to all endocrinologists in B.C.

  We are getting the listings from the websites of the various provincial/territorial Colleges of Physicians and Surgeons. However, there is currently no listing by specialty for Saskatchewan, Nova Scotia, NWT, or Nunavut. As well, there are no endocrinologists listed for PEI or Yukon, so we will use either 'internal medicine' or the general listing for these areas. If you can help obtain a listing for any of these areas, please contact the Newsletter Editor.

Living with Addison's Disease for over Fifty Years:

I was first diagnosed with Addison's disease when I was 14 years old (1959). I am now 65.

Having Addison's disease when there was very little available information, or the ease of communication that we have now, was very frustrating. I read every book I could find with any mention of Addison's disease but there was very little offered. Even the doctors could not give you a lot of information. It was when I went to Toronto St. Michael's Hospital for training to be a Medical Record Librarian, where I had complete access to the medical library, that I finally found information – oh, what a goldmine of information I found!

I did not meet another Addisonian till I was in my late 40's and that was a very special day for me.

There are some personal thoughts and beliefs that I have realized over these last fifty years that I would like to share with you.

Firstly and most important – you need to look after yourself to the best of your ability. That means being an active advocate in your medical care, exercising to the best of your ability (walking is good), eating the best foods that you can afford to eat and trying to live in as stress free an environment as you can using relaxation techniques, yoga, listening to quiet music - whatever works for you.

Finding a good family doctor and endocrinologist is so very important to your medical health. If you have a doctor who will not listen to you or asks you to take up a regimen that you are not comfortable with, question him/her to explain why they feel this is so necessary, and if that gets you nowhere, move on. Some doctors are very good “on paper” only but lack the people skills to be a caring and responsible physician for your continued good health.

Taking the least amount of medication that your body needs to function normally is very important for you. So many doctors do not want to take the time to “fine tune” your medication to the lowest dose necessary to maintain your good health without putting you in jeopardy. They also need to educate you WHEN to increase your medications, HOW LONG to take those higher doses and the healthy way to CUT BACK to your normal dose. So many Addisonians take far too much medication because it is easiest for the doctors to manage your case, but is not necessarily best for you as a patient. Too much medication can produce the same type of symptoms as too little medication, so the amounts keep going up and up and up, but the side effects can keep going up and up, too. That is not what you want for optimum health.

Having an emergency injection kit available is imperative. Know when to use it and how to use it properly. If your doctor will not give it to you, do your research and find any and all information you can on the positive aspects of having a kit and give it to him or her to plead your case.

I have found that the combination of homeopathic/natural medicines and traditional medicines are the best for me. Again, find a homeopath or naturopath with good credentials and one that knows about Addison’s disease.

Addison’s disease is part of my life but it does not control my life.

Life is a journey and each and every day has something to offer. If you feel you are just treading water sometimes, that is okay too. Look around and enjoy the view.

I wish everyone good health and much happiness.

Submitted by Joan Southam
jsoutham@rogers.com

MRSA:

MRSA is the acronym for Mycin Resistant Streptococcus Aureus. There is lots of information about it on Wikipedia. One startling fact is that up to 20% of the population is a carrier, and whether or not it takes hold is largely dependent on your general health. An Addisonian with a weak autoimmune system would seem to be a prime target.

I was amazed at how fast it attacked my toe. I was overtired at the time, and there was a delay in doing a swab at the local emergency room. Within a few days, despite treatment with antibiotics, it was obvious that the result would be amputation.

Two rules to follow.

1) Avoid becoming overtired.

2) If you develop an infection, always request that your doctor, or Emergency Room staff, take a swab of the infected area to determine what the most effective medication would be.

Submitted by John Gordon

Highlights from Local Meetings:

Vancouver Island Support Group

Our next meeting will be Saturday, October 2, in Room 1814 at the Victoria General Hospital, 1:00 to 3:00PM. Please note that the Vancouver Lower Mainland support group will be hosting the Canadian Addison Society AGM on October 16.

For further information on the Vancouver Island Support Group, please contact Jim Sadlish at wx6999@gmail.com or (250) 656-6270.

If anyone in the Mid Island area would be interested in an information get-together, please contact Barbara Hunn.

For information on Central Island activities, please contact Barbara Hunn at bhunn@shaw.ca or (250) 714-0036 or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

Our next meeting will be the AGM which we are hosting Saturday, October 16, 2010, 1:00 to 4:30, in the Sherbrooke Building, Sherbrooke Lounge, 260 Sherbrooke Street, New Westminster, BC.

For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton, or Peter Little at peterbettyt66@gmail.com or (780) 918-2342 in Edmonton.

Saskatchewan Support Group

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

Southern Ontario Support Group

The next scheduled meeting for the South/Central Ontario Support Group is Saturday, October 2, 2010, in the Community Room at the Brantford Police Station, 344 Elgin Street, Brantford, Ontario N3T 5T3. Registration starts at 12.30 pm and the meeting will commence at 1.00 pm. Our Guest Speaker will be Dr. Stan Van Uum, who will present the results of the recent Hair Cortisol Study and explain what this may mean to Addisonians. As well, Dr. Van Uum will accommodate a question and answer session, as time permits. See you in Brantford, Oct 2.

Submitted by Harold Smith

For further information on the South/Central Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith9995@rogers.com or (519) 742-9995.

Eastern Ontario Support Group

The next meeting will be at Robbie's Italian Restaurant, 1531 St Laurent Boulevard, Ottawa, at noon on Saturday October 16, 2010.

For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

We now have a local representative, Marie-Josée Normand, in Montréal. If you wish to contact her, she can be reached at (514) 376-2712, by email at marijonormand@videotron.ca or through the ‘Local Groups’ page of our website.

Nous avons maintenant une représentante, Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au marijonormand@videotron.ca, ou bien par l'entremise de notre site-web.

Atlantic Support Group

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Medical Q & A

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (http://www.addisonsociety.ca/faq.html), or see previous issues of the newsletter.

Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.

Q: I was diagnosed with Addison's in January 1998. My symptoms were not typical. After years of questioning, I have learned that my hypothalmus, thyroid and pituitary glands are, for lack of a better word, also malfunctioning and have been told the adrenal problem is a result of this. I have been taking 15 mg. of Cortef for a number of years and have never experienced any real benefits from it, but many side effects. They are significant weight gain, osteoporosis, chronic insomnia, extreme fatigue, loss of muscle mass, depleted potassium, bouts of depression, and a generally feeling of tiredness that worsens every year. I now lead a very reclusive life and have great difficulty in performing the simplest household chores. In truth, I just feel like resting in bed 90% of the time. My family refuses to believe any of this, and I have been labelled lazy, attention seeking, etc. I am now scheduled for diabetes tests. Has anyone else been experienced these multiple endocrine gland disorders? If so, how are they coping?

> **A:** I am sorry to hear that you have gone through such a long period of treatment only to feel progressively worse. The combination of problems that you are experiencing could be due to several possible causes. You should be seeing an endocrinologist who can review your symptoms and the laboratory data that is available and discuss with you how it all fits together.
>
> The hypothalamus is part of the brain and it releases small peptide hormones that control the hormones secreted by the pituitary gland. These pituitary hormones control thyroid function, adrenal function, ovarian/testicular function and other functions such as growth. Problems in the hypothalamus or the pituitary can affect one or more of these functions.

> It is also possible that several hormone-producing glands can be affected by an autoimmune process in which antibodies are directed to proteins in the gland, causing damage to the gland such that its hormone output is compromised. The adrenal and the thyroid are commonly affected in this way.
>
> It is possible to determine whether or not your problem is related to one of these processes by appropriate testing. This is why it is important to see an endocrinologist who can carry out the appropriate investigations to determine the nature of your difficulties. I am sure that there is an answer to your concerns but be sure you look in the right place.

Q: I take 10 mg of cortef in the am and 2.5 mg prednisone in the afternoon. Because I had no energy in the morning upon rising, I have recently had to increase my dosage of prednisone to 5 mg. I have since noticed that I am having trouble getting to sleep and staying asleep. Would it make any difference if I took the prednisone in the am, and took the cortef in the pm? I know that prednisone takes longer to 'kick in', but it also lasts longer in the system.

> **A:** Some endocrinologists like to use prednisone in the treatment of Addison's disease because of its long duration of action to carry overnight. In the non-Addisonian individual, the blood levels of cortisol go down to close to undetectable levels during the night. There is still cortisol inside the cell to carry on the normal activities. These low blood levels may be important to allow the cells to readapt as cortisol is secreted episodically starting about 4:00 AM to get peak levels by about 8:00AM.
>
> I prefer to use cortisol only given two or preferably three times a day usually first thing in the AM and sometime in the afternoon, or AM, noon and late afternoon. This routine would allow you to sleep better. You must discuss this with your endocrinologist. He or she may have specific reasons why you are on the regimen that you are on and they would have to work out the dose of cortisol with you if there is a change.

Q: I was diagnosed with Addison's Disease in January 2007, when I was 57 years old. I was prescribed 5 mg Prednisone in the morning and 2.5 mg at dinner, as well as Florinef 0.05 mg in the morning. A few months later, my family doctor prescribed Pantoloc 40 mg to be taken twice a day because of my stomach ache, which he felt was due to the prednisone. After a year, I realized that Prednisone made me feel very sick. My head felt heavy and I felt like my mind was in fog most of the time. I had no energy and I could not concentrate on things that I needed to do in my job as a teacher. I also developed excess facial hair. In July 2008, the prednisone prescription was changed to a Cortisol 20 mg tablet dosage. This was to be taken 25 mg. in the morning and 12.5 mg. at dinner time. I am also taking Prozac, 20 mg a day because of severe depression, sleeping pills (Zoplicone 7.5 mg.) 1 tablet at night, and Fosamax 70 mg, 1 tablet a week because I cannot take Calcium. I tried to see if vitamins might increase my energy and also my doctor had me try taking Alertec. After taking these for a while, I did not have any change in my energy level, but I had severe stomach aches.

My concern is that after three years on medication, my health does not improve at all. I feel very tired, depressed, have a lack of concentration, body pain, lower back pain, dizziness, headaches, and stomach ache. I need to urinate every hour, still feel like I have a "foggy" brain and I have gained 15 pounds in the last three years. I have tried to keep a balanced diet and I am walking nearly every day for exercise, but I do not always have the strength or motivation to do it.

> **A:** The treatment that you received initially would be appropriate for an individual with Addison's disease. If the original diagnosis was correct, I would have expected you to feel somewhat better if not much better. The fact that things have not improved and may be a little worse would make me want to reassess the information on which the original diagnosis was made.
>
> I think you should make an appointment with your endocrinologist and review the basis for the diagnosis and your response to treatment. This will give her/him an opportunity to show you how the tests confirmed the diagnosis and how the medication is designed to improve your symptoms. It is possible that some of your symptoms are related to problems other that Addison's disease.

Q: My daughter has primary Addison’s, and is now being investigated for POTS (Postural Orthostatic Tachycardia Syndrome). Her cardiologist is going to do a tilt table test. He has admitted that he is not familiar with Addison’s, so I am concerned that if my daughter should pass out during the test, it could bring on a crisis. There is also a possibility that they may give her blood pressure lowering medication during the test - I am wondering how this will affect the Addison’s.

Also, in these kinds of situations, how would one go about getting two specialists (the cardiologist and the endocrinologist) to confer with each other, as I am sure that would help to alleviate the uncertainty of having procedures done by doctors who have little knowledge of Addison’s.

> **A:** One of the symptoms of Addison's disease is postural hypotension if they are not adequately replaced with Florinef to give adequate salt retention. The cardiologist should be aware that your daughter has Addison's disease and the medication she is on. In an individual with Addison's disease who is on treatment, the tilt table test would not precipitate a crisis. It is unlikely that they would give her any blood pressure lowering medication.
>
> I am actually surprised that someone with Addison's disease would be investigated for POTS unless she had been perfectly well for a prolonged period and then developed these symptoms rather suddenly. My first approach would be to make sure her adrenal meds were optimized.

Q: I have Addison's and hypothyroidism. I am on 7.5 mg of prednisone, 0.1 mg florinef and 0.088 mg synthroid. I was prescribed osteoforte 50,000 IU a number of years ago by my endocrinologist when I started to experience bone loss and was diagnosed as having osteopenia. I also started taking actonel and have been on both ever since, probably 10 years or more. Now with the new knowledge regarding the benefits of vitamin E, I noticed my multivitamin now has 600 IU. Would this not be too much? Is osteoforte the same as vitamin E?

Also there have been some new studies regarding calcium supplements contributing to heart disease. Have you heard of this? I usually only end up taking two 300mg tablets a day with magnesium and try to get the rest through food which can be difficult as I don't drink milk.

> **A:** Osteoforte is vitamin D2, a vitamin D of vegetable origin. It has the same activity as vitamin D3, the kind you make yourself when exposed to the sun. Fifty thousand units is a significant dose, it depends how often you take it. Vitamin D is stored in fat tissue so 50,000 units a month would be reasonable. It would be worthwhile getting your blood level checked. The current recommended dose is 1000 to 2000 units per day.
>
> Vitamin E is a different vitamin. It usually comes in 400 or 800 unit tablets and is not usually involved in bone metabolism.
>
> There has been a small study suggesting that calcium is associated with heart attacks. It is felt that this is not a significant study and no other studies using calcium have shown any similar effect. I think you are quite safe taking two 300mg calcium tablets daily and if you do not eat dairy products, you need this much calcium.

Q: I have Addison's disease and currently take 20 mg hydrocortisone daily. I have been nauseated and light-headed lately and my doctor recommended I double up on the hydrocortisone for a week. I was not instructed any further and after the week was up, I went back to the normal 20 mg. I am experiencing anxiety and panic along with upset stomach, so much that daily life is limited. Would this be caused by the sudden decrease in hydrocortisone? Should I have decreased slowly back to the normal amount? What should I do now? I live in a rural area and contact with my endocrinologist is minimal and not very often.

> **A:** I am assuming that you were feeling well on 20mg of hydrocortisone before your recent problem occurred. I am also assuming that you felt better when you doubled up on your hydrocortisone. I hope that these assumptions are correct. If you felt well on 40mg of hydrocortisone, then it would be wise go back to this dose then to cut it back by 5mg every 2 to3 days. This would help your body adjust to the change and would help you to know at what dose you felt well. It would also be a good idea to check your dose of Florinef. Your family doctor can do this by measuring your electrolytes and your plasma renin.

Q: My wife had Addison’s disease when she gave birth to 2 children. She's since passed away and I'm now dealing with behavioural issues with my 5-year-old (the oldest). Talking to a child psychologist, they mentioned that children whose mothers have Addisons through pregnancy often develop behavioural and psychological issues. Is this true and what am I to expect?

> **A:** I have not heard anything about children of Addison's mothers having problems with behavioural or psychological issues. I would ask the psychologist for references that suggest this. I would very much like to review any articles that support this suggestion. If the mother is on appropriate medication during the pregnancy, I don't see any reason why there would be any negative effects on the foetus

Q: It has recently been realized that I have too much calcium in my blood. No diagnosis has been reached yet. Is this related in any way to Addison's? I have Addison's Disease and Celiac Disease. If it turns out to be Parathyroid Disease, where in Canada is a good parathryoid surgeon? Is it okay to have any surgeon perform this surgery? Is it likely to be cancer?

> **A:** There may be several reasons why your calcium could be high. The first thing your family doctor will do is measure your parathyroid hormone level. If this is elevated, it suggests an overactived parathyroid gland, and if not she/he will do other investigations to determine the cause. It is possible that the Addison's disease could be related, but this would only occur if you were not taking enough cortisol or if you were dehydrated.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#, by emailing liaisonsecretary@addisonsociety.ca or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.